

Media Watch...

is intended as an advocacy, research and teaching tool. The weekly report is international in scope and distribution – to colleagues who are active or have a special interest in **hospice** and **palliative care**, and in the quality of **end-of-life care** in general – to help keep them abreast of current, emerging and related issues – and, to inform discussion and encourage further inquiry.

22 May 2017 Edition | Issue #513



Compilation of Media Watch 2008-2017 ©

Compiled & Annotated by Barry R. Ashpole

Universal issues in advancing access to quality end-of-life care: Scroll down to [Specialist Publications](#) and 'The palliative care challenge: Analysis of barriers and opportunities to integrate palliative care in Europe in the view of national associations' (p.11), *Journal of Palliative Medicine*.

Canada

Learning to live with cancer

THE NATIONAL POST | Online – 19 May 2017 – Nowhere else in medicine is the battle rhetoric more entrenched than in cancer. And it's defeating people. Military metaphors can push people into accepting brutal treatments or "maximum tolerated doses" of chemotherapy when there's little hope of extending survival. They keep people from accepting palliative treatment ... because it seems too much like surrendering, while driving others to demand needlessly aggressive treatments for cancers that would likely never kill them. Framing cancer as a kind of war within our bodies can also seriously harm a person's emotional psyche. "Who wants to go to war with themselves?" radiation oncologist Edward Halperin, of New York Medical College, writes...¹ "How is it ever helpful to think of oneself as a victim who was randomly attacked and now you're trying to kill your assailant in order to survive?" For some, the war imagery, the determination to "hit hard and hit fast," can be empowering... [However,] studies have shown people who are encouraged to "fight" and "be positive" are more likely to conceal their own emotional distress. <https://goo.gl/wJgXXA>

Specialist Publications

'Dying from cancer: Communication, empathy, and the clinical imagination' (p.17), in *Journal of Patient Experience*.

'Aid – When there is "nothing left to offer": A survey and qualitative study of ethics and palliative care during international humanitarian emergencies' (p.19), in *Prehospital & Disaster Medicine*.

1. 'Military metaphors and the consequences of the language of cancer,' *Practical Radiation Oncology*, 2017;7(1):1-3. <https://goo.gl/KJRZhr>

Noted in Media Watch 15 May 2017, #512 (p.10):

- *ONCOLOGY NURSING NEWS* | Online – 6 May 2017 – '**Battle weary: When discussing cancer, military terminology doesn't help.**' Promotions for cancer centers or fundraisers, as well as conversations between patients and their healthcare providers or loved ones, often focus on the idea of "fighting" or "battling" cancer. But how do these military metaphors ... affect the outlook and coping ability of patients? And what do they accomplish when it comes to motivating those without cancer to engage in preventive measures? <https://goo.gl/jOFHbL>

Of the \$2.7 billion cancer charities spent in 2013, only 45% went towards fighting cancer

THE NATIONAL POST | Online – 16 May 2017 – A *National Post* analysis of cancer charities in 2013, the most recent year with tax return data available, found 67 registered breast cancer charities. That amounts to one-fifth of all cancer charities in the country, far more than any other type of cancer. Prostate came in a distant second with 17 charities. Not only did the *Post's* analysis of the complex and sometimes opaque world of cancer funding show great disparities in dollars among cancer types, it also revealed the inefficiencies in the sector – and the paltry amounts that actually go to finding a cure. In 2013, Canada's hundreds of cancer charities spent \$2.7 billion in total, but only 45% went towards fighting cancer in multiple ways, including supporting patients, awareness, advocacy, as well as research. Fifty-five percent, or about \$1.5 billion, went to fundraising costs, salaries and other overhead. The \$644 million that Canadians contributed to cancer charities in 2013 exceeds the total actually spent on research that year. That's because the money goes to cover many things in addition to research. <https://goo.gl/Mj2NgL>

N.B. See 'Right to Care: Palliative care for all Canadians,' Canadian Cancer Society, December 2016. [Noted in Media Watch 18 January 2016, #445 (p.1)] <http://goo.gl/f3iFEB>

Palliative home care in Ontario: What's the standard?

ONTARIO | CBC News – 16 May 2017 – Researchers from Wilfrid Laurier University in Waterloo saw a gap in knowledge when it comes to the quality of Ontario's palliative home care, so they started looking at data gathered by local care centres across the province to find out what kind of care patients are receiving. Dawn Guthrie, a professor from the department of kinesiology and physical education, led the one-year research project [the final results of which are pending formal publication]... "Gathering some information about how we're doing right now with some actual numbers paves the way for asking those questions about how do we do better, what does it look like across Ontario," said Guthrie in an interview... "What initiatives could we put in place, or strategies to improve the quality of care and then ultimately that leads to the best possible care provided." The data was gathered through local Community Care Access Centres, which are mandated by the province to assess clients who receive home care every six months... The patients are assessed on their physical and mental health. Researchers looked at the responses of over 500,000 people and spoke to palliative care experts for their opinions on which factors can be used determine quality of care. <https://goo.gl/FyQ0pR>

Noted in Media Watch 4 July 2016, #469 (p.2):

- ONTARIO | Health Quality Ontario – 28 June 2016 – '**Ontarians are talking about end-of-life care, yet for many, palliative care may begin too late or not at all, new report finds.**' Almost 60% of people in Ontario who die receive palliative care (PC) services, according to a new report by Health Quality Ontario.¹ And among those who have a record of receiving PC, about half begin to receive it in their last month of life. <http://goo.gl/4iQXTu>

1. 'Palliative Care at the End of Life,' Health Quality Ontario, June 2016. <http://goo.gl/GW0Xh9>

Noted in Media Watch 14 March 2016, #453 (p.2):

- ONTARIO | *The Ottawa Citizen* – 11 March 2016 – '**Numerous gaps in Ontario's system for palliative care, report finds.**' The way Ontario's health system cares for the dying is full of holes that need patching, Ottawa South Member of the Provincial Parliament John Fraser says in an official report the provincial government is to use as a guide to those fixes.¹ <http://goo.gl/GEFYP1>

1. 'Palliative & End-of-Life Care Provincial Roundtable Report,' Ontario Minister of Health & Long-Term Care, March 2016. <http://goo.gl/eRyw8K>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- ONTARIO | *Toronto Sun* – 18 May 2017 – **‘Take us out of assisted dying referral process: Doctors.’** Many Ontario doctors and nurses working in palliative care say their objection to playing a role in assisted suicides may force them to leave the medical profession, the message about two dozen physicians, nurses and pharmacists brought to Queen’s Park ... prior to the introduction of Tory Member of the Provincial Parliament Jeff Yurek’s private member’s bill (Bill 129), which is designed to amend the Medical Assistance Dying Statute Law. <https://goo.gl/je0P6G>
- MANITOBA | CBC News (Winnipeg) – 16 May 2017 – **‘Manitoba bill aims to protect staff unwilling to offer assisted death.’** Medical professionals in Manitoba who refuse to help terminally ill patients die will be protected from reprisals under new legislation... Bill 34, the Medical Assistance in Dying (Protection for Health Professionals & Others) Act, will ensure staff cannot be compelled to go against their own religious or ethical beliefs. The move follows announcements last year from two Winnipeg faith-based hospitals, Concordia Hospital (Anabaptist-Mennonite) and St. Boniface Hospital (Catholic), which said they will not provide the service to patients. Bill 34 would also ban any professional regulatory body from requiring members to participate in medically assisted deaths. <https://goo.gl/LAzDhK>

Specialist Publications

‘End-of-life care’ (p.21), in *Canadian Family Physician*.

U.S.A.

Like hunger or thirst, loneliness in seniors can be eased

KAISER HEALTH NEWS | Online – 18 May 2017 – It’s widely believed that older age is darkened by persistent loneliness. But a considerable body of research confirms this isn’t the case. In fact, loneliness is the exception rather than the rule in later life. And when it occurs, it can be alleviated: It’s a mutable psychological state. Only 30% of older adults feel lonely fairly frequently, according to data from the National Social Life, Health & Aging Project, the most definitive study of seniors’ social circumstances and their health in the U.S. The remaining 70% have enough fulfilling interactions with other people to meet their fundamental social and emotional needs. “If anything, the intensity of loneliness decreases from young adulthood through middle age and doesn’t become intense again until the oldest old age,” said Louise Hawkley, an internationally recognized authority on the topic and senior research scientist at the National Opinion Research Center at the University of Chicago. Understanding the extent of loneliness is important, insofar as this condition

has been linked to elevated stress, impaired immune system function, inflammation, high blood pressure, depression, cognitive dysfunction and an earlier-than-expected death in older adults. A new study, co-authored by Hawkley, highlights another underappreciated feature of this affliction: loneliness is often transient, not permanent.¹ <https://goo.gl/LB24H6>

Specialist Publications

‘The humanity in end-of-life care’ (p.16), in *Health Affairs*.

‘Aggressive care at the end-of-life for younger patients with cancer: Impact of American Society of Clinical Oncology’s Choosing Wisely campaign’ (p.9), in *Journal of Clinical Oncology*.

‘Rehumanizing birth and death in America’ (p.16), in *Society*.

1. ‘Transitions in loneliness among older adults: A 5-year follow-up in the National Social Life, Health & Aging Project,’ *Research on Aging*, published online 17 March 2017. <https://goo.gl/2vUwNZ>

Cont.

Noted in Media Watch 12 December 2016, #491 (p.3):

- PENNSYLVANIA | *The Pittsburgh Post-Gazette* – 2 December 2016 – ‘**Alone and aging: Creating a safety net for isolated seniors.**’ Phyllis Krantzman represents a universe that’s come to be known among geriatric specialists as “elder orphans” – seniors with no relatives to help them deal with physical and mental health challenges. Their rising numbers prompted the American Geriatrics Society this week to unveil guidelines for a segment of these older adults who can no longer make their own medical decisions and have no designated surrogates.¹ <https://goo.gl/Nlv5yG>

1. ‘Making medical treatment decisions for unbefriended older adults,’ *Journal of the American Geriatric Society*, published online 22 November 2016. [Noted in Media Watch 28 November 2016, #489 (p.11)] <https://goo.gl/68dZQy>

Noted in Media Watch 1 April 2013, #299 (pp.7-8):

- *PROCEEDINGS OF THE NATIONAL ACADEMY OF SCIENCES* | Online – 25 March 2013 – ‘**Social isolation, loneliness, and all-cause mortality in older men and women.**’ In this study, both social isolation and loneliness were associated with increased mortality. However, the effect of loneliness was not independent of demographic characteristics or health problems and did not contribute to the risk associated with social isolation. Although both impair quality of life and well-being, efforts to reduce isolation are likely to be more relevant to mortality. <https://goo.gl/6PdqmY>

Noted in Media Watch 25 June 2012, #259 (p.4):

- *JAMA INTERNAL MEDICINE*, 2012;172(14):1078-1884. ‘**Loneliness in older persons: A predictor of functional decline and death.**’ This is one of the first studies in a nationally representative population to examine the relationship between loneliness and functional decline and death. There have been few studies examining loneliness as a predictor of specific health outcomes. Several smaller studies are consistent with the authors’ findings that loneliness in older persons is associated with poor health outcomes and may even be linked to nursing home admission. <http://goo.gl/cj2Ufa>

Massachusetts Senate focuses on pediatric palliative care

MASSACHUSETTS | *Newburyport News* – 18 May 2017 – One hundred and sixty-five Massachusetts families are on a waiting list for palliative care (PC) services for their terminally ill children, according to senators who said they hope to take another shot at ending that wait in their fiscal 2018 budget. As the Senate Ways & Means Committee presented its \$40.3 billion budget, Vice Chairman Sal DiDomenico touted the inclusion of \$2.6 million in funding for pediatric PC services, saying the money would allow for the waiting list to be “wiped out.” The state’s pediatric PC network provides services such as counseling and case management to children “to achieve an improved quality of life and to meet the physical, emotional and spiritual needs experienced during the course of illness, death and bereavement,” according to the state law establishing the program. The law says children with “life-limiting” illnesses, including cancer, AIDS and congenital anomalies, can be eligible. <https://goo.gl/ilcs87>

Noted in Media Watch 30 May 2016, #464 (p.11):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 24 May 2016 – ‘**Cost analysis and policy implications of a pediatric palliative care program.**’ In 2010, California launched Partners for Children (PFC), a pediatric palliative care pilot program offering hospice-like services for children eligible for full-scope Medicaid delivered concurrently with curative care, regardless of the child’s life expectancy. The average per enrollee per month (PEPM) health care costs of program enrollees decreased by \$3,331 from prior to their participation in PFC to the enrolled period, driven by a reduction in inpatient costs of \$4,897 PEPM. PFC enrollees experienced a nearly 50% reduction in the average number of inpatient days per month, from 4.2 to 2.3. Average length of stay per hospitalization dropped from an average of 16.7 days prior to enrollment to 6.5 days while in the program. <http://goo.gl/83nGDu>

America's Health Rankings: Senior Report 2017

UNITED HEALTH FOUNDATION | Online – Accessed 17 May 2017 – The report provides a comprehensive analysis of senior population health on a national and state-by-state basis across 34 measures of senior health. The report's model is based on the historical America's Health Rankings model of health and was adapted in 2013 for the senior population under the guidance of an advisory group of experts in the fields of aging and senior health. Notably, the premature death rate among seniors increased in the past year after three consecutive years of decline, a trend that mirrors the trajectory of years of potential life lost before age 75 in the general population. Nationally, clinical care measures – hospital readmissions, preventable hospitalizations, hospital deaths and hospice

care use – have improved since the first Senior Report was published in 2013. In many cases, these are promising trends that reflect consistent improvements each year from 2013 to 2017. <https://goo.gl/vvV1Ro>

Extract from *Senior Report 2017* (p.51)

The number of individuals receiving hospice care increased 243% from 3.5% in 2000 to 12% in 2014. Older adults accounted for 84% of hospice patients in 2014. Medicare covers certified services for patients with a prognosis of six months or less of life; more than 85% of hospice patients were covered by the Medicare hospice benefit in 2014.

Noted in Media Watch 22 February 2016, #450 (p.3):

- DARTMOUTH INSTITUTE FOR HEALTH POLICY & CLINICAL PRACTICE | The Dartmouth Atlas Project (extract) – 17 February 2016 – ***Our Parents, Ourselves: Health Care for an Aging Population.*** Rates of hospice referral across the U.S. often do not reflect patient preferences, which tend to favor comfort measures over medical intervention. Referrals to hospice care that are done too late also adversely affect the quality of care, the reported experiences of patients and families, and their satisfaction with the health care system. <http://goo.gl/dcXa6C>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- NEVADA | *Las Vegas Journal-Review* – 15 May 2017 – **'Nevada Senate panel OKs doctor-assisted death measure.'** Senate Bill 261 ... was passed on a 3-2 party-line vote by the Senate Health & Human Services Committee, with Republicans voting no. The bill allows patients who are 18 or older, of sound mind and given six months or fewer to live, to request a prescription from their doctor to end their life at the time of their choosing. Physicians, pharmacists and health care facilities would not be mandated to participate. <https://goo.gl/mLr8Bl>

International

Older Australians opting for in-home care over nursing homes

AUSTRALIA | ABC News – 20 May 2017 – While consumers are demanding more flexible services, structural reforms are forcing aged care providers to change the way they operate. In February, the Federal Government restructured aged care funding, allocating home care packages to individuals rather than aged care providers. A recent study by the national Cognitive Decline Partnership Centre suggested there may also be significant financial benefits from home care. Researchers analysed data from 541 residents at 17 aged care facilities around Australia, comparing outcomes for people in traditional residential care compared to those living in smaller, home-like facilities. The study assessed health as well as financial outcomes, including staffing, catering, laundry and corporate costs. Preliminary results showed residents in group homes had fewer hospital admissions and scored higher on quality of life measures, with overall costs 20% lower than for traditional care. <https://goo.gl/TwnlVI>

Dying at home banned in French town due to lack of doctors

FRANCE | *Daily Sabah* (Istanbul, Turkey) – 18 May 2016 – The mayor of Laigneville Municipality, in northern France, has announced that dying at home within the borders of the municipality has temporarily been banned. Mayor Christophe Dietrich said the law created by the city's council is primarily symbolic, but the town's struggle to provide the necessary services to people who die in their homes is very real. With a population of 5,000 and only two physicians offering medical services to the entire town, Laigneville doctors are hard-pressed to keep up with the demand. Dietrich said people often have to wait four to six hours for a doctor to pronounce death. The mayor said the doctors will retire at the end of the year, and nobody has been appointed to replace them. In the end, Mayor Dietrich realizes the new law cannot actually be enforced, but the aim is to draw attention to the town's need for doctors. "I know that this whole thing is ridiculous, but we are facing a ridiculous situation," the mayor said. <https://goo.gl/zizUCe>

Finite lives: Dying, death and bereavement – an examination of State Services in Ireland

IRELAND | An independent report by Senator Marie-Louise O'Donnell – 18 May 2017 – The key recommendations from this study involve the government reviewing its services, developing supports that are fit-for-purpose and championing the right to a dignified death at home and abroad. The research in this report shows that end-of-life (EoL) is relevant to every arm of the State. While many departments did not have a policy in relation to dying, death and bereavement, almost all were engaged in activities or had developed protocols and practices in response to the recognised needs of people facing dying, death and bereavement. It was also understandable that departments do not have policies on EoL as the State itself has no overarching strategy. EoL is corralled into health strategies covering palliative care, dementia, carers and older people. Therefore, it is natural that people defer to the Department of Health on issues around dying, death and bereavement. Yet people who experience death are citizens and will be attending school as a pupil or teacher; they will be at work; they are family members; they will live in homes that need adaptation as their illness progresses; they will need transportation to live and socialise and get to health appointments; they may be compelled to apply for income supports to cover their growing medical and living expenses... In most cases, they will approach the State for support.

N.B. This report is Senator O'Donnell's second on end-of-life care in Ireland (see below). Government Departments, the Office of Public Works, and the Office of the Revenue Commissioners were involved. The Department of Health, however, was not included. Download Senator O'Donnell's report at the website of Senator Marie Louise O'Donnell: <https://goo.gl/UA4q9r> **BRA**

Noted in Media Watch 7 December 2015, #439 (p.6):

- IRELAND | *The Independent* (Dublin) – 4 December 2015 – '**Death and bereavement not just a family issue when it comes to our civil servants.**' There are almost 30,000 civil servants in Ireland today. They represent a cross section of Irish society. They are the wheels of government. A silent people who do their best to ensure the workings of State. There are almost 30,000 civil servants in Ireland today. They represent a cross section of Irish society. They are the wheels of government. A silent people who do their best to ensure the workings of State. This is why the report I have written, 'Finite Lives – Part 1 – A Report on How the Civil Service Deals with Dying, Death and Bereavement Among its Own Members,' is unique.¹ <https://goo.gl/sbA2R6>

1. The report was prepared by Independent Senator Marie Louise O'Donnell following an initiative by Taoiseach (Head of the Irish Government) Enda Kenny. <https://goo.gl/pk9qmg>

Palliative Care Network Community

Closing the Gap Between Knowledge & Technology

<http://goo.gl/OTpc8I>

Guatemala: Thousands face needless end-of-life suffering

GUATEMALA | Human Rights Watch – 17 May 2017 – Thousands of patients with advanced illnesses in Guatemala suffer unnecessarily from severe pain because they cannot get appropriate pain medications, reports Human Rights Watch.¹ The report documents how Guatemala’s drug control regulations – meant to prevent drug abuse – make it almost impossible for many patients with cancer and other advanced illnesses to get strong pain medicines like morphine. Guatemala’s lack of effort to ensure access to palliative care (PC), regulatory barriers, and needlessly restrictive and complex regulations on controlled substances condemn many patients with pain to needless suffering, with devastating consequences for them and their families. Only four public or government-supported hospitals offer PC: all are in Guatemala City, although nearly 80% of the population lives elsewhere. Although the Ministry of Health formally created a PC commission in December 2011, Guatemala still does not have a policy or strategy to develop PC and ensure it is available outside the country’s capital. The country’s only public medical school does not teach PC and pain management as part of its undergraduate curriculum; only one of the three private medical schools does. <https://goo.gl/7QBZMR>



1. 'Punishing the patient': Ensuring access to pain treatment in Guatemala,' Human Rights Watch, May 2017. <https://goo.gl/p26hEV>

End-of-life care in New Zealand

Trained to treat: Why doctors treat the dying, even when they know it's futile

NEW ZEALAND | Stuff.co.nz (Wellington) – 16 May 2017 – It's one of the many dilemmas doctors face: if a patient is dying, and you know treatment won't help, do you still treat anyway? Professor Lindy Willmott, from the Australian Centre for Health Law Research [Brisbane, Queensland], set out to discover why most doctors still do, even in a world where they, and their budgets, are under ever-growing strain. There was a perception in clinical settings that "there must be something more that can be done," she said. She carried out a survey of 96 doctors and medical staff in Queensland [Australia] public hospitals in an effort to help understand where unnecessary treatment was happening, and make the experience of death better for people. The vast majority of staff surveyed treated dying people because they believed, as doctors, they were trained to treat. "Doctors felt it difficult to not offer something because it made them feel as if they weren't doing their job. The default is to keep treating." Doctors are not under legal duty to provide treatment they don't believe will benefit the patient – sometimes referred to as "futile" treatment, Willmott said. She shared the results with colleagues at the [recent] Australian & New Zealand College of Anaesthetists conference. <https://goo.gl/Xv84n6>

South Koreans' medical expenditures before death soar: Data

SOUTH KOREA | Yonhap News Agency (Seoul) – 14 May 2017 – South Koreans' medical expenditures spent a year before death jumped more than threefold over the past decade, reflecting the rising need to beef up the country's hospice facilities and services. According to the National Health Insurance Service, South Koreans aged 40 and above on average spent 15.9 million won (US\$14,127) over the one-year period before death in 2015, soaring from 4.7 million won posted in 2005. The organization said while the increase came as hospitals offer more services to the patients due to the development of medical technology, it is also attributable to the lack of hospice facilities that can accommodate terminally ill patients. <https://goo.gl/7SZKmt>

Cont.

Noted in Media Watch 20 June 2016, #467 (p.13):

- *KOREAN JOURNAL OF HOSPICE & PALLIATIVE CARE*, 2016;19(2):99-108. '**Hospice palliative care in South Korea: Past, present, and future.**' Hospice and palliative care in Korea has developed steadily since its introduction in 1965. Currently, it is targeted only towards terminal cancer patients and their families, and the national health insurance scheme covers only inpatient hospice care for said patients. <http://goo.gl/Aa6FL3>

End-of-life care in England

Staff shortages and increased caseloads prevent effective pain management at home for dying people

U.K. (England) | Hospice UK & National Council for Palliative Care – 13 May 2017 – Only around half of healthcare professionals who support dying people at home say staffing levels are sufficient to meet their pain management needs according to new research.¹ Fifty-one per cent of those surveyed said staffing levels were sufficient to meet needs, while more than a third said they were not. And many healthcare professionals supporting dying people are over-stretched with one in five of those surveyed describing their caseload as “not manageable.” Nearly a third of respondents described the availability of end-of-life care (EoLC) training in their area as either “requiring improvement” or “inadequate.” A quarter of those surveyed said they had no access 24/7 telephone EoLC advice for people at the end of life, their families and carers. The joint report sets out new guidance for service providers and Clinical Commissioning Groups to help improve pain management for dying people at home. It reinforces existing policy guidelines on EoLC.^{2,3} <https://goo.gl/Lolrfk>

1. 'No painful compromise: A guide for commissioners and providers to improve pain management for dying people at home,' Hospice UK & National Council for Palliative Care, May 2017. Commissioned by National Health Service England. <https://goo.gl/62ei6R>
2. 'Ambitions for Palliative & End-of-Life Care: A National Framework for Local Action 2015-2020,' National Palliative & End-of-Life Care Partnership, September 2015. [Noted in Media Watch 14 September 2015, #427 (p.14)] <http://goo.gl/1cXKFe>
3. 'Care of dying adults in the last days of life,' National Institute for Health & Care Excellence, December 2015. [Noted in Media Watch 21 December 2015, #441 (p.7)] <https://goo.gl/xNcV19>

Noted in Media Watch 20 March 2017, #504 (p.3):

- U.K. (England) | *The Daily Telegraph* – 14 March 2017 – '**National Health Service rationing “leaving dying patients to suffer in pain” report warns.**' National Health Service England rationing is leaving dying patients to suffer in pain, a leading think tank has warned. A report by The King's Fund found people at the end of their life are being left for hours without pain relief due to nursing shortages.¹ <https://goo.gl/JybU9p>

1. 'Understanding National Health Service financial pressures: How are they affecting patient care?' The King's Fund, March 2017. <https://goo.gl/Fs4Hh1>

Specialist Publications

'How many people [in England & Wales] will need palliative care in 2040? Past trends, future projections and implications for services' (p.11), in *BMC Medicine*.

'The development of palliative care hospital support teams in Bavaria from 2011-2015: Tasks, acceptance, structure and funding' (p.14), in *Das Gesundheitswesen*.

'First mapping study for palliative care development in the Eastern Mediterranean Region and Africa' (p.14), from the Institute of Culture & Society (Madrid, Spain).

'The palliative care challenge: Analysis of barriers and opportunities to integrate palliative care in Europe in the view of national associations' (p.11), in *Journal of Palliative Medicine*.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- AUSTRALIA (Victoria) | *The Australian* (Melbourne) – 17 May 2017 – ‘**Hiding euthanasia as cause of death to protect life insurance payouts.**’ Life insurance payouts of Victorians who access euthanasia would be protected by hiding it as an official cause of death under recommendations before the independent taskforce designing the framework. The taskforce has been advised that voluntary assisted dying should not be considered as a “reportable death” and excluded from being listed on death certificates. Instead, the terminal illness that drove the person to access euthanasia should be listed as the cause of death, thereby protecting relatives who stand to inherit their wealth. Most of the 300 stakeholders the taskforce consulted said it should protect the privacy of the dead and ensure families aren’t robbed of life insurance claims, with suicide excluded from some claims. The taskforce ... has also been advised to include a provision in the legislation that would exempt doctors from criminal or civil liability if they legally assisted a death. <https://goo.gl/YjJYYg>

Specialist Publications

Choosing wisely? Measuring the burden of medications in older adults near the end of life: Nationwide, longitudinal cohort study [in Sweden]

AMERICAN JOURNAL OF MEDICINE | Online – 27 April 2017 – The authors identified over half a million adults over 65 years of age who died in Sweden between 2007 and 2013, and reconstructed their drug prescription history for each of the last 12 months of life through the Swedish Prescribed Drug Register. The study resulted in two main findings. First, the burden of medications increases as death approaches. The proportion of older adults exposed to at least ten different prescription drugs rose from 30% to 47% over the course of the last year before death. Older adults who died from cancer had the largest increase in the number of drugs. Individuals living in institutions were found to receive a greater number of medications than those living in the community, but the number of drugs increased more slowly for those living in an institution. Second, the researchers found that polypharmacy near the end of life (EoL) is fueled not only by drugs prescribed for the purpose of symptom management, but also by the frequent continuation of long-term preventive treatments and disease-targeted drugs. The clinical benefit of drugs aiming at preventing cardiovascular diseases during the final month of life is at the very least questionable. Physicians should consider discontinuing drugs that may be effective and otherwise appropriate, but whose potential harms outweigh the benefits that patients can reasonably expect before death

occurs. The authors noted that the process of de-prescribing requires timely dialogue between the patient, family, and physician, and close monitoring of symptoms. It is also essential that patients and their relatives receive clear information about their options in terms of palliative care in order to counter the feeling of abandonment that they may experience when treatments are withdrawn. The authors call for the development of clinical guidelines to support physicians in their effort to reduce potentially futile drug treatments near the EoL. <https://goo.gl/zAoQJ5>

Aggressive care at the end-of-life for younger patients with cancer: Impact of American Society of Clinical Oncology’s Choosing Wisely campaign

JOURNAL OF CLINICAL ONCOLOGY | Online – Accessed 16 May 2017 – 71-76% of patients [studied] across different cancers received aggressive care within the last 30 days of life, including 30-35% of patients who died in the hospital. Rates of aggressive care use between early 2012 before Choosing Wisely vs. 2014 were unchanged in patients with colorectal and breast cancers; and, increased in lung, pancreatic and prostate cancers. On the other hand, hospice use ranged from 14-18% across cancers. Multivariable models showed regional variations in aggressive care and hospice use. There is substantial overuse of aggressive end-of-life care among younger patients with incurable cancers. <https://goo.gl/YdTEUU>

Cont.

Noted in Media Watch 4 April 2016, #456 (p.4):

- *NEW ENGLAND JOURNAL OF MEDICINE*, 374(13):1203-1205. ‘**The science of “choosing wisely”:
Overcoming the therapeutic illusion.**’ The Choosing Wisely campaign may be an ambitious attempt to address the problem of overtreatment, but it’s not realistic to think that any single solution will be effective. The reliance on medical societies risks a certain parochial defensiveness, which has produced recommendations focused disproportionately on other specialties’ procedures. <http://goo.gl/j37hGT>

Noted in Media Watch 2 March 2015, #399 (p.8):

- *JAMA INTERNAL MEDICINE* | Online – 25 February 2015 – ‘**Challenges in Choosing Wisely’s international future.**’ Since its 2012 launch by the American Board of Internal Medicine Foundation, the Choosing Wisely campaign has affected more than 60 U.S. specialty societies. The campaign is becoming an international phenomenon. <http://goo.gl/tpc6QI>

Living into death: A case for an iterative, fortified and cross-sector approach to advance care planning

ANTHROPOLOGY & MEDICINE | Online – 16 May 2017 – Advance care planning (ACP) has been framed as best practice for quality palliative care (PC), yet a growing body of literature affirms the need for an early iterative ACP process to begin when people are young and healthy. A significant gap appears to exist in the literature regarding the utility of death conversations outside the end-of-life context. Could “death conversations” early in life be an effective tool by which doctor and patient can co-construct a more healthful way of life, and realistic relationship with death? And, what variables must be taken into account for these conversations to proceed successfully? This paper provides a narrative exploration of the value of death conversations in the clinical context in New Zealand. Five exemplars are discussed, drawn from a sample of 21 semi-structured interviews with young older adults (54-65 years old) not receiving PC or diagnosed with a terminal illness. <https://goo.gl/gqps8t>

Media Watch: Editorial Practice

Each listing in Media Watch represents a condensed version or extract of what is broadcast, posted (on the Internet) or published; in the case of a journal article, an edited version of the abstract or introductory paragraph, or an extract. Headlines are as in the original article, report, etc. There is no editorializing ... and, every attempt is made to present a balanced, representative sample of “current thinking” on any given issue or topic. The weekly report is issue-oriented and offered as a potential advocacy, research and teaching tool.

Distribution

Media Watch is distributed at no cost to colleagues active or with a special interest in hospice, palliative care and end of life issues. Recipients are encouraged to share the weekly report with *their* colleagues. The distribution list is a proprietary one, used exclusively for the distribution of the weekly report and occasional supplements. It is not used or made available for any other purpose whatsoever – to protect the privacy of recipients and also to avoid generating undue e-mail traffic.

Links to Sources

1. Short URLs are used in Media Watch. Links to pdf documents, however, cannot always be shortened.
2. Links are checked and confirmed as active before each edition of the weekly report is distributed.
3. Links often remain active, however, for only a limited period of time.
4. Access to a complete article, in some cases, may require a subscription or one-time charge.
5. If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.
6. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

Something Missed or Overlooked?

If you are aware of a current report, article, etc., relevant to hospice, palliative care or end-of-life issues not mentioned, please alert this office (contact information below) so that it can be included in a future issue of Media Watch. Thank you.

How many people [in England & Wales] will need palliative care in 2040? Past trends, future projections and implications for services

BMC MEDICINE | Online – 18 May 2017 – Current estimates suggest that approximately 75% of people approaching the end-of-life may benefit from palliative care (PC). The growing numbers of older people and increasing prevalence of chronic illness in many countries mean that more people may benefit from PC in the future, but this has not been quantified. By 2040, annual deaths in England & Wales are projected to rise by 25.4% (from 501,424 in 2014 to 628,659). If age- and sex-specific proportions with PC needs remain the same as in 2014, the number of people requiring PC will grow by 25.0% (from 375,398 to 469,305 people/year). However, if the upward trend observed from 2006 to 2014 continues, the increase will be of 42.4% (161,842 more people/year, total 537,240). In addition, disease-specific projections show that dementia (increase from 59,199 to 219,409 deaths/year by 2040) and cancer (increase from 143,638 to 208,636 deaths by 2040) will be the main drivers of increased need. Healthcare systems must now start to adapt to the age-related growth in deaths from chronic illness, by focusing on integration and boosting of PC across health and social care disciplines. Countries with similar demographic and disease changes will likely experience comparable rises in need. <https://goo.gl/7H1Tr9>

The palliative care challenge: Analysis of barriers and opportunities to integrate palliative care in Europe in the view of national associations

JOURNAL OF PALLIATIVE MEDICINE | Online – 16 May 2017 – This article investigates levels of integrated PC in European countries. Barriers and opportunities directly related to PC integration were identified and analyzed thematically according 1) to the dimensions of the World Health Organization (WHO) public health model, and 2) by the degree of service provision in each country. Forty-three barriers and 65 opportunities were identified as being related to PC integration. Main barriers were: 1) Lack of basic PC training, with a particular emphasis on the absence of teaching at the undergraduate level; 2) Lack of official certification for professionals; 3) Lack of coordination and continuity of care for users and providers; 4) Lack of PC integration for non-cancer patients; 5) Absence of PC from countries' regulatory frameworks; and, 6) Unequal laws or regulations pertaining to PC within countries. Innovations in education and new regulatory frameworks were identified as main opportunities in some European countries, in addition to opportunities around the implementation of PC in home care, nursing home settings, and the earlier integration of PC into patients' continuum of care. With increasing provision of services, more challenges for the integration are detected. <https://goo.gl/xmwAKm>

Noted in Media Watch 6 March 2017, #502 (p.8):

- *BRITISH MEDICAL JOURNAL* | Online – 27 February 2017 – ‘Palliative care from diagnosis to death.’ Late palliative care (PC) is a missed opportunity to do better for patients, families, and health services. In high income countries, up to 80% of people who die could benefit from PC much earlier in their illness. The World Health Organization adopted a resolution on early PC in 2014.¹ It states that PC should be considered from diagnosis onwards and integrated into care for people with any condition that means they may die in the foreseeable future. <https://goo.gl/GFlusO>

1. ‘Strengthening of palliative care as a component of integrated treatment within the continuum of care,’ Sixty-seventh World Health Assembly, World Health Organization, January 2014. <https://goo.gl/fqSHlb>

Noted in Media Watch 27 May 2013, #307 (p.10):

- *PALLIATIVE MEDICINE* | Online – 21 May 2013 – ‘How many people need palliative care? A study developing and comparing methods for population-based estimates.’ Understanding the need for palliative care (PC) is essential in planning services. Expert panel review of all deaths in England, 2006-2008 identified changing practice (e.g., extension of PC to more non-cancer conditions), changing patterns of hospital/home care and multiple, rather than single, causes of death as important. The authors estimate a minimum of 63.03% of all deaths needing PC. <https://goo.gl/5tz9RQ>

Improving hospital-based end-of-life care processes and outcomes: A systematic review of research output, quality and effectiveness

BMC PALLIATIVE CARE | Online – 19 May 2017 – There is a lack of methodologically rigorous studies in the field of end-of-life care (EoLC). Publications examining EoLC in hospitals are predominately descriptive in nature, with few rigorous trials of interventions aimed at improving the care of the dying. More high-quality intervention trials in hospitals are required to make clear recommendations about which strategies are most effective in improving EoLC processes, and whether these improvements translate to improved end-of-life outcomes. Interventions targeting both the patient and their substitute decision maker, and those strategies with the potential to change practice patterns at a system level should be explored. <https://goo.gl/2sVJun>

Selected articles on evidenced-based end-of-life care

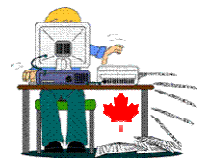
- *THE ASCO POST* (American Society of Clinical Oncology) | Online – 10 December 2015 – ‘**Evidence-based practice needed in end-of-life care.**’ Over the past several decades, the oncology community has advanced the implementation of guidelines and other assessment tools to further integrate solid clinical evidence into daily practice, from diagnosis to treatment. However, the delivery of equitable, high-quality end-of-life care has suffered from a lack of study-based evidence. [Noted in Media Watch 14 December 2015, #440 (p.6)] <http://goo.gl/eudqG7>
- *NEW ENGLAND JOURNAL OF MEDICINE* | Online – 14 October 2015 – ‘**Toward evidence-based end-of-life care.**’ One of the most sobering facts is that no current policy or practice designed to improve care for millions of dying Americans is backed by a fraction of the evidence the Food & Drug Administration would require to approve even a relatively innocuous drug. [Noted in Media Watch 19 October 2015, #432 (p.14)] <http://goo.gl/qH3rMQ>
- *JOURNAL OF PALLIATIVE CARE*, 2015;31(3):133-140. ‘**Evidence-based palliative care 13 years on: Has anything changed?**’ There is a paucity of data on whether interventions in individual palliative care (PC) units are evidence-based. Results show the evidence base for interventions in PC continues to evolve, but that there are still areas for which further high-quality studies are needed. [Noted in Media Watch 7 September 2015, #426 (p.12)] <http://goo.gl/4VJ90P>

Disturbed grief: Prolonged grief disorder and persistent complex bereavement disorder

BRITISH MEDICAL JOURNAL | Online – 18 May 2017 – Each individual's grief process is unique. The concept of stages of grief occurring in a specific order is a popular, yet inadequate representation of what grieving people go through. Traditional models developed to understand grief therefore often unhelpfully suggest that all bereaved individual do, and even should, follow the same process towards recovery from loss. The newer grief task model offers a more neutral framework to describe normal and disturbed grief. The model proposes that normal grief is the successful achievement of certain “grief tasks,” whereas complications in managing these tasks might indicate disturbed grief. There is no recommended or specific order in which to achieve these tasks. Grief tasks include: to accept the reality of the loss; to process the associated pain; to adjust to a world without the deceased; and, to find an enduring connection with the deceased in the midst of embarking on a new life. The model also describes challenges faced following losses other than bereavement <https://goo.gl/BQT1b3>

[Barry R. Ashpole](#)

My involvement in hospice and palliative care dates from 1985. As a communications consultant, I've been involved in or responsible for a broad range of initiatives at the community, regional, provincial and national level. My current work focuses primarily on advocacy and policy development in addressing issues specific to those living with a terminal illness – both patients and families. In recent years, I've applied my experience and knowledge to education, developing and teaching on-line and in-class college courses on different aspects of end-of-life care, and facilitating issue specific workshops, primarily for frontline care providers. Biosketch on the International Palliative Care Resource Center website at: <http://goo.gl/5CHoAG>



What is inappropriate hospital use for elderly people near the end of life? A systematic review

EUROPEAN JOURNAL OF INTERNAL MEDICINE | Online – 11 May 2017 – The definition of “inappropriate admissions” near the end of life incorporated system factors, social, and family factors. The prevalence of inappropriate admissions ranged widely depending largely on non-clinical reasons: poor availability of alternative sites of care or failure of preventive actions by other healthcare providers, family requests or too late an admission to be of benefit. The widespread use of subjective parameters not routinely collected in practice, and the inclusion of non-clinical factors precluded the true estimation of clinical inappropriateness. Clinical inappropriateness and system factors that preclude alternative community care must be measured separately. They are two very different justifications for hospital admissions, requiring different solutions. Society has a duty to ensure availability of community alternatives for the management of ambulatory-sensitive conditions and facilitate skilling of staff to manage the terminally ill in non-acute settings. Only then would the evalua-

tion of local variations in clinically inappropriate admissions and inappropriate length of stay be possible to undertake. <https://goo.gl/t3iMJl>

A U.S. perspective

Are hospital/emergency department transfers less likely among nursing home residents with do-not-hospitalize orders?

JOURNAL OF POST-ACUTE & LONG-TERM CARE MEDICINE, 2017;18(5):438-411. The results of this study [of residents of nursing homes in New York State] show that 61% of nursing home residents had do-not-resuscitate orders, 12% had feeding restrictions, and only 6% had do-not-hospitalize (DNH) orders. Residents with DNH orders had significantly fewer hospital stays ... and ED visits ... in the last 90 days than those without DNH orders. Efforts should be made to encourage nursing home residents to complete DNH orders to promote integration of the resident's values and goals in guiding care provision toward the end of life. <https://goo.gl/GvVqsw>

Noted in Media Watch 5 December 2016, #490 (p.3):

- *JAMA INTERNAL MEDICINE* | Online – 28 November 2016 – ‘**Avoiding hospitalizations from nursing homes for potentially burdensome care: Results of a qualitative study.**’ Nursing home residents are often hospitalized for care that has the potential to be burdensome, in the sense that the risks outweigh the expected benefits. These hospitalizations offer little hope of improving quality of life or changing the course of illness... Certain facilities are more successful than others at preventing potentially burdensome hospitalizations. <https://goo.gl/M3lzDh>

Noted in Media Watch 25 July 2016, #472 (p.5):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 21 July 2016 – ‘**Interventions for reducing hospital readmission rates: The role of hospice and palliative care.**’ Previous research has not examined exactly how hospitals may promote the appropriate use of hospice and palliative care (PC) for their discharged patients. A positive effect for hospitals participating in the State Action on Avoidable Readmissions initiative was enhanced engagement in efforts to promote greater use of hospice and PC in reducing unplanned readmissions. <http://goo.gl/nwpwsE>

N.B. Additional articles on avoidable hospitalisations in the context of end-of-life care are noted in the 18 July 2016 (#471, p.14) and 14 March 2016 (#455, p.12) issues of Media Watch.



Media Watch Online

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing p.20.

The development of palliative care hospital support teams in Bavaria from 2011-2015: Tasks, acceptance, structure and funding

DAS GESUNDHEITSWESSEN (The Health Care System) | Online – 15 May 2017 – Palliative care hospital support teams (HPCTs) provide inpatients from all departments palliative medical support. Seriously ill as well as dying patients, who are being treated in facilities that do not have their own palliative care (PCU) unit, can benefit from these multi-professional teams just as much as patients who do not (yet) need to be admitted to a PCU. At the end of 2015, 53 HPCTs, which were in accordance with the requirements established in the Program for HPCTs by the Bavarian Ministry of Health in 2009, had been approved in Bavaria. HPCTs were widely regarded as a suitable instrument for improving in-house palliative care... The level of acceptance among the other departments of the hospital was assessed as being significantly higher in 2015 than it was 4 years earlier. HPCTs cover various tasks, most commonly including “supportive conversations,” “accompaniment in the dying phase,” “pain therapy” and “discharge management.” However, a decline in multi-professionalism within the teams could be seen, especially in the fields of psychology/psycho-oncology and spiritual care. HPCTs in Bavaria take over important tasks in caring for seriously ill and dying patients and their families. According to their own appraisal, the level of acceptance within hospitals is improving. The hope is that new regulations ... will solidify funding without jeopardizing the multi-professionalism that characterizes HPCTs. <https://goo.gl/ChymaL>

N.B. German language article.

Home as a place of caring and wellbeing? A qualitative study of informal carers and caring networks lived experiences of providing in-home end-of-life care

HEALTH & PLACE, 2017;46:58-64. Although the burden of caring is well described, the value of home as a potential place of well-being and support for informal caring networks when providing end-of-life care is not well recognised. Interviews and focus groups with primary carers and members of informal care networks revealed their collaborative stories about caring for a dying person at home. Four themes emerged: 1) Home as a place of comfort and belonging; 2) Places of social connection and collaborative caring; 3) Places of connection to nature and the non-human; and 4) Places of achievement and triumph. When support is available, nurturing carer wellbeing may be best achieved at home. <https://goo.gl/BY3ufX>

First mapping study for palliative care development in the Eastern Mediterranean Region and Africa

INSTITUTE OF CULTURE & SOCIETY, UNIVERSITY OF NAVARRA (Madrid, Spain) | Online – 20 May 2017 – There is limited palliative care (PC) development in Africa, but there is also a significant improvement in the number of countries with hospice and PC services, compared to previous reports. Improvements in advocacy are identified, with more than half of the countries in Africa reporting a national PC association. In Eastern Mediterranean countries (EMC) information on the state of palliative care (PC) development is scant. The EMC study is the first of its kind in conducting a systematic descriptive analysis of PC development in the region. PC remains underdeveloped in most countries. The two mapping studies were introduced at the recent World Congress of the European Association for Palliative Care in Madrid, Spain.



N.B. Links to studies: Africa – <https://goo.gl/NDtpYQ>; Eastern Mediterranean – <https://goo.gl/Kli86q>

Noted in Media Watch 15 March 2017, #503 (p.14):

- *THE LANCET ONCOLOGY*, 2017;18(3):e176-e184. ‘**Barriers to, and opportunities for, palliative care development in the Eastern Mediterranean Region.**’ Several barriers exist to development and expansion of palliative care (PC) delivery in this region, including the absence of PC in national policies, little partnership working, insufficient PC education for health-care professionals and volunteers, poor public awareness, and gaps in access to essential pain-relief medicines. <https://goo.gl/iL9vYI>

Areas of control desired by patients and families referred to hospice care: Perspectives of hospice admissions staff

JOURNAL OF APPLIED GERONTOLOGY | Online – 15 May 2017 – Sense of control in end-of-life care plays a critical role in the patient's well-being. However, little is known about the areas of control essential to patients and families at a specific time point in the illness trajectory: when patients stop curative treatments and are referred to hospice. Sixteen admissions staff members from four hospice agencies were interviewed about their perceptions of areas in which patients and families worried about losing control by accepting hospice. The thematic analysis revealed four areas of control: 1) Changes to medical care; 2) Health care provider changes; 3) Use of life-sustaining treatments; and, 4) Daily life. Participants put a great emphasis on consistently communicating their willingness to honor patients' and families' control over their care decisions and lives. <https://goo.gl/VvCgUq>

The experiences of staff who support people with intellectual disability on issues about death, dying, and bereavement: A metasynthesis

JOURNAL OF APPLIED RESEARCH IN INTELLECTUAL DISABILITIES | Inprint – 13 May 2017 – Historically, people with intellectual disabilities have tended to be excluded from knowing about death, dying, and bereavement. Staff in intellectual disability services can play a valuable role in improving understanding of these issues in those they support. Thirteen papers were identified following a systematic review of six databases. Three themes were developed following a lines-of-argument synthesis: 1) Talking about death is hard: negotiating the uncertainty in death, dying, and bereavement; 2) The commitment to promoting a "good death"; and, 3) The grief behind the professional mask. "A cautious silence: The taboo of death," was an overarching theme. A more open culture around issues of death, dying, and bereavement in intellectual disability settings is essential and could be promoted through staff training and support. <https://goo.gl/84206X>

Noted in Media Watch 10 April 2017, #507 (p.12):

- *JOURNAL OF INTELLECTUAL DISABILITY RESEARCH* | Online – 7 April 2017 – 'Investigating the factors that affect the communication of death-related bad news to people with intellectual disabilities by staff in residential and supported living services: An interview study.' Most staff working in intellectual disability services will be confronted with people with intellectual disabilities who need support around death, dying and bereavement. Staff [i.e., study participants] found supporting people with intellectual disabilities around death and dying extremely difficult and tended to avoid communication about the subject. <https://goo.gl/MPN8db>

N.B. Additional articles on end-of-life care for people living with intellectual and developmental disabilities are noted in this issue of Media Watch and in the 6 March 2017 (#502, p.12) issue of the weekly report.

End-of-life in the U.S.

The Cambia Sojourns Scholars Leadership Program: Conversations with emerging leaders in palliative care

JOURNAL OF PALLIATIVE MEDICINE | Online – 19 May 2017 – There is a pressing workforce shortage and leadership scarcity in palliative care (PC) to adequately meet the demands of individuals with serious illness and their families. To address this gap, the Cambia Health Foundation launched its Sojourns Scholars Leadership Program in 2014, an initiative designed to identify, cultivate, and advance the next generation of PC leaders. This report summarizes the second cohort of Sojourns Scholars' projects and their reflection on their leadership needs. Three themes emerged from descriptions of the scholars' project experience: 1) Challenges in PC practice; 2) Leadership strategies in PC; and, 3) Three lessons learned to be a leader were identified. Challenges included perceptions of PC, payment and policy, and workforce development. Educating and collaborating with other clinicians and influencing policy change

Cont.

are important strategies used to advance PC. Time management, leading team effort, and inspiring others are important skills that promote effectiveness as a leader. Providing comprehensive, coordinated care that is high quality, patient and family centered, and readily available depends on strong leadership in PC. <https://goo.gl/HEVLFY>

Related

- *HEALTH AFFAIRS* | Online – 19 May 2017 – ‘**The humanity in end-of-life care.**’ Health care is personal, especially when it comes to caring for someone as they approach death. However, half of Americans feel they have too little control over end-of-life (EoL) medical decisions. As the industry moves toward a more holistic approach to care delivery, health care organizations are beginning to re-think how they treat patients and starting to embed end-of-life care (EoLC) plans into the overall approach earlier on, sometimes before people even become ill. In a recent report on EoLC ... several principles are discussed that take a broader view around caring for seriously ill patients, helping to ensure that care is sensitive, aligned with patient and family wishes, and always working toward enhanced quality of life. One of the top recommendations in the report to achieving that end is increasing emphasis on palliative care. <https://goo.gl/KL85GB>
- 1. ‘Improving care at the end of life: A report of the Aspen Institute Health Strategy Group,’ March 2017. <https://goo.gl/XVPJRU>
- *SOCIETY* | Online – 12 May 2017 – ‘**Rehumanizing birth and death in America.**’ Despite spending more on medical care than any other country in the world, the U.S. still boasts some of the worst patient outcomes of any developed nation. This disparity is especially true of how Americans give birth and die. These natural human transitions have become catastrophically expensive and leave patients and their families traumatized from unnecessary interventions. This article examines the costs and outcomes associated with the medicalization of birth and death and argues that alternatives exist that improve patient outcomes while lowering costs. <https://goo.gl/ETtxgx>

Palliative care and Parkinson’s disease: Caregiver perspectives

JOURNAL OF PALLIATIVE MEDICINE | Online – 18 May 2017 – The objective of this paper was to elicit Parkinson’s disease (PD) caregiver needs, salient concerns, and preferences for care using a palliative care (PC) framework. Caregivers [i.e., study participants] desired access to emotional support and education regarding the course of PD, how to handle emergent situations (e.g., falls and psychosis), and medications. Participants discussed the immediate impact of motor and non-motor symptoms as well as concerns about the future, including: finances, living situation, and caretaking challenges in advanced disease. Caregivers commented on the impact of PD on their social life and communication issues between themselves and patient. All participants expressed interest and openness to multidisciplinary approaches for addressing these needs. Caregivers of PD patients have considerable needs that may be met through a PC approach. Caregivers were receptive to the idea of multidisciplinary care in order to meet these needs. <https://goo.gl/lxw9bl>

N.B. Additional articles on palliative care for people living with Parkinson’s disease are noted in the 27 March 2017 (#505, p.12), 28 November 2016 (#489, p.6), and 11 April 2016 (#457, p.12) issues of Media Watch.

Dying from cancer: Communication, empathy, and the clinical imagination

JOURNAL OF PATIENT EXPERIENCE | Online – 11 May 2017 – Medical oncologists and patients with advanced cancer struggle to discuss prognosis, goals, options, and values in a timely fashion. As a consequence, many patients die receiving aggressive treatment potentially inconsistent with their fully informed preferences and experience increased symptom burden and distress. The goals of patient - oncologist communication include exchanging information, building relationship, and engaging in shared decisions. Empathy is perhaps especially essential to effective patient – oncologist communication when the end of life (EoL) is approaching. He authors speculate that, in addition to being a skilled response to a patient's negative emotions, empathy is an emergent property of the relationship that allows the patient and oncologist to imagine what it will be like to navigate the transition from living with to dying from cancer; and, to prepare for the transition. They propose that effective empathy: 1) Requires an attentive, curious and imaginative physician; 2) Acknowledges the complex and shifting goals as the EoL approaches; and, 3) Begins with a willingness of physicians to check in and find out what she

may have misunderstood or misperceived. Empathy in EoL conversations cultivates the shared experiences necessary to co-create the new goals of care that underlie excellent EoL care. <https://goo.gl/76xmPX>

Communicatively constructing the bright and dark sides of hope: Family caregivers' experiences during end of life cancer care

BEHAVIORAL SCIENCES | Online – 15 May 2017 – The current study examines the bright and dark sides of how hope is communicated across the cancer journey from the vantage point of bereaved family caregivers. Two overarching patterns of hope emerged. Those who experienced hope as particularized (focused on cure) cited communication about false hope, performing (“faking it”), and avoidance. Those who transitioned from particularized to generalized hope (hope for “a good death”) reported acceptance, the communication of hope as social support, prioritizing family, and balancing hope and honesty. Interventions should encourage concurrent oncological and palliative care, increased perspective-taking among family members, and encourage the transition from particularized to generalized hope. <https://goo.gl/bQLEbL>

Noted in Media Watch 9 January 2017, #494 (p.6):

- *CLINICAL ONCOLOGY* | Online – 30 December 2016 – **‘Too hot, too cold or can we get it just right? What emotional distance should oncologists keep from their patients?’** The doctor/patient relationship may be short and intensive or one lasting for many years. Until fairly recently, a formal paternalistic relationship was the norm in medicine; this has now been replaced by a more patient-centred approach. An unintended consequence of the move towards less formal relationships may be the loss of the emotional protection to the doctor. <https://goo.gl/qT09i5>

Media Watch 19 December 2016, #492 (p.12):

- *JOURNAL OF THE ROYAL SOCIETY OF MEDICINE*, 2016;109(12):446-452. **‘Empathy, sympathy and compassion in healthcare: Is there a problem? Is there a difference? Does it matter?’** This paper argues that there is currently a problem in the balance between scientific-technical and psychosocial elements of patient care. A broad model of empathy is suggested which could replace the vaguer concepts of sympathy and compassion and so enable improvements in patient care, psychosocial research and medical education. <https://goo.gl/E9byLi>

Seeing is believing – healthcare professionals’ perceptions of a complex intervention to improve care towards the end of life: A qualitative interview study

PALLIATIVE MEDICINE | Online – 18 May 2017 – Methods to improve care, trust and communication are important in acute hospitals. Complex interventions aimed at improving care of patients approaching the end of life (EoL) are increasingly common. While evaluating outcomes of complex interventions is essential, exploring healthcare professionals’ perceptions is also required to understand how they are interpreted; this can inform training, education and implementation strategies to ensure fidelity and consistency in use. Three views emerged regarding the purpose of a complex intervention towards the EoL:

Cont.

labelling/categorising patients, tool to change care delivery, and serving symbolic purpose indirectly affecting behaviours of individuals and teams. All impact upon potential utility of the intervention. Participants described the importance of training and education alongside implementation of the intervention. However, adequate exposure to the intervention was essential to witness its potential added value or embed it into practice. <https://goo.gl/JFrel0>

Related

- *THE LANCET* | Online – 16 May 2017 – ‘**Being CAREFuL about improving end-of-life care in hospitals.**’ Although practices and preferences for the location of end-of-life care (EoLC) vary between countries, cultures, and individuals, many people die in hospitals. Studies exploring how to better provide compassionate and effective EoLC in hospitals are important and needed. <https://goo.gl/UsTP4Q>

End-of-life care in the U.K.

Recommendations to reduce inequalities for LGBT people facing advanced illness: ACCESSCare national qualitative interview study

PALLIATIVE MEDICINE | Online – 14 May 2017 – Discrimination experienced by lesbian, gay, bisexual and/or trans (LGBT) people facing advanced illness is unjust and at odds with legislation. Focused efforts are needed to improve care experiences for LGBT people through public health strategies to address issues in accessing care, and training and education, to address deficits in care delivery, focusing on knowledge, skills and attitudes of health-care professionals. Five main themes emerged in this study: 1) Person-centred care needs that may require additional/different consideration for LGBT people (including different social support structures and additional legal concerns); 2) Service level or interactional (created in the consultation) barriers/stressors (including heteronormative assumptions and homophobic/transphobic behaviours); 3) Invisible barriers/stressors (including the historical context of pathology/ criminalisation, fears and experiences of discrimination); and, 4) Service level or interactional facilitators (including acknowledging and including partners in critical discussions). These all shape 5) Individuals’ preferences for disclosing identity. This study identifies 10 simple, low-cost recommendations for individuals, services and institutions, to improve care for LGBT people facing advanced illness [see table below]. Through working collaboratively with LGBT communities..., we can enact a culture shift by increasing expectations for person-centred care and improving care delivery. <https://goo.gl/SgdfVb>

Individual level	Avoid using heterosexually framed or assumption-laden language Demonstrate sensitivity in exploration of sexual orientation or gender history Respect individuals’ preferences regarding disclosure of sexual identity or gender history Carefully explore intimate relationships and significant others, including biological and chosen family (friends)
Service/institutional level	Explicitly include partners and/or significant others in discussions Make clear statement of policies and procedures related to discrimination Include content regarding LGBT communities in training on diversity and discrimination Increase LGBT visibility in materials (in written content and images) Provide explicit markers of inclusion (e.g. rainbow lanyards or pin badges) Initiate partnerships and/or engagement with LGBT community groups

Noted in Media Watch 27 March 2017, #505 (p.8):

- *GERIATRICS* | Online – 16 March 2017 – ‘**Healthcare and end-of-life needs of lesbian, gay, bisexual, and transgender older adults: A scoping review.**’ To some extent, our ability to draw inferences about the experience of lesbian, gay, bisexual, and transgender (LGBT) older adults across jurisdictions is limited given the current state of the literature. Continued research in this area is particularly timely given that several countries are experiencing a demographic shift and a movement towards inclusivity. This shift is noted through reports on LGBT aging and end of life released in the U.K. and Australia. Taking a life course perspective necessitates an understanding of the personal histories and historical context in which LGBT older adults are situated. <https://goo.gl/VEyPch>

Cont.

Noted in Media Watch 24 October 2016, #484 (p.7):

- *BMJ SUPPORTIVE & SUPPORTIVE CARE*, 2016;6(3):388. ‘**Care experiences of lesbian, gay, bisexual and/or trans people facing life-limiting illness: A qualitative interview study.**’ Five main themes emerged: 1) Palliative care needs that may require additional or different consideration for lesbian, gay, bisexual and/or trans people; 2) Communicative or service level barriers and stressors, including heteronormative assumptions, and homophobic/transphobic behaviours; 3) Internalised or invisible barriers and stressors, including fears, or experiences, of discrimination; 4) Which shape individuals’ preferences for disclosure and exploration of identity; and, 5) Communicative or service level facilitators to accessing care and support. <https://goo.gl/OELgVf>

N.B. Additional articles on end-of-life care for LGBT communities are noted in the 23 May 2016 (#463, p.3) and 8 February 2016 (#448, p.16) issues of Media Watch.

Aid – When there is “nothing left to offer”: A survey and qualitative study of ethics and palliative care during international humanitarian emergencies

PREHOSPITAL & DISASTER MEDICINE | Online – 20 April 2017 – There is a lack of evidence clarifying ethical and practical possibilities and consequences of humanitarian organizations, addressing or failing to address patients’ palliative needs. This study sought to inform realistic, context-sensitive guidance, education, and practice for the provision of palliative care (PC) during humanitarian emergencies. Beginning with a survey of international aid organizations, the authors aimed to identify a baseline of current PC provisions for clinical and psychosocial care in humanitarian action. Survey results and preliminary analysis of interviews is shared. Responses cover: 1) Preparedness to deliver PC in humanitarian emergencies (e.g., disasters, conflict areas, epidemics); 2) Resources currently available to support the delivery of PC in humanitarian contexts; and, 3) Ideas/concerns related to integration of PC into humanitarian healthcare. PC is an area of growing global concern. It is increasingly recognized as necessary, yet simultaneously seen as outside the realm of possibility, particularly in humanitarian settings, where care in life-threatening conditions may be logistically and ethically challenging. <https://goo.gl/CFrrGf>

N.B. The full text of this article is available at <https://goo.gl/YMmHX3>; click on

Request full-text

Noted in Media Watch 17 April 2017, #508 (p.11):

- *THE LANCET* | Online – 15 April 2017 – ‘**Palliative care in humanitarian crises: Always something to offer.**’ More than 128.6 million people across 33 countries require life-saving humanitarian assistance, 92.8 million of whom are particularly vulnerable. Palliative care (PC), however, has been omitted from efforts to tackle humanitarian crises. The authors propose holistic PC as an integral component of relief strategies. PC is especially applicable in four humanitarian scenarios. <https://goo.gl/vnGfgr>

Noted in Media Watch 13 March 2017, #503 (p.2):

- HUMANITARIAN HEALTH ETHICS RESEARCH NETWORK | Online – Accessed 8 March 2017 – ‘**Palliative care in humanitarian situations – is it achievable?**’ We can assume that where populations experiencing humanitarian emergencies remain in their home country, any pre-existing level of need for palliative care would persist or even increase under the additional strains of the emergency (depending on the humanitarian situation). <https://goo.gl/MSvXTT>

Noted in Media Watch 30 January 2017, #497 (p.12):

- *PALLIATIVE MEDICINE* | Online – 23 January 2017 – ‘**Palliative care in humanitarian medicine.**’ Palliative care (PC) interventions have historically been neglected in the practice of humanitarian medicine. This may come as a surprise since it is a sombre reality medical practitioners are frequently witness to death and dying in their response to humanitarian crises. At the World Health Assembly in May 2014, the World Health Organization affirmed a commitment to develop and implement policies that integrate PC services across the continuum of care. <https://goo.gl/Yxb8uB>

Dignity-conserving care actions in palliative care: An integrative review of Swedish research

SCANDANAVIAN JOURNAL OF CARING SCIENCES | Online – 16 May 2017 – Previous research has proposed that persons in need of palliative care (PC) often have a loss of functions and roles that affects social and existential self-image. Moreover, these individuals also commonly suffer from complex multi-symptoms. This, together with the situation of facing an impending death, can lead to a loss of dignity. Therefore, supporting these persons' dignity is a crucial challenge for professional nurses. The 'Dignity Care Intervention' addresses the multi-dimensionality of dignity by identifying patients' dignity-related concerns and suggests care actions to address them. At the present, the 'Dignity Care Intervention' is adapted for implementation in Swedish care settings. Because expressions of dignity are influenced by culture, and an overview of care actions in a Swedish context is lacking, this integrative review aimed to find suggestions from Swedish research literature on what kind of care actions can preserve dignity. The review offers culturally relevant suggestions on how to address specific dignity-related concerns. The adapted 'Dignity Care Intervention' will be a way for Swedish nurses to provide person-centred PC that will conserve patients' dignity. <https://goo.gl/XiHvQs>

N.B. Additional articles on ensuring dignity in the context of end-of-life care are noted in the 4 January 2016 issue of *Media Watch* (#443, p.8).

[Media Watch: Online](#)

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://goo.gl/JXsJtr>

INTERNATIONAL PALLIATIVE CARE RESOURCE CENTER: <http://goo.gl/frPgZ5>

PALLIATIVE CARE NETWORK COMMUNITY: <http://goo.gl/8JyLmE>

PALLIMED: <http://goo.gl/7mrgMQ> [Scroll down to 'Aggregators' and Barry Ashpole and Media Watch]

Asia

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: <HTTP://GOO.GL/JNHVMB>

SINGAPORE | Centre for Biomedical Ethics (CENTRES): <https://goo.gl/JL3j3C>

Canada

ONTARIO | HPC Consultation Services (Waterloo Region Wellington County): <https://goo.gl/IOSNC7>

Europe

EUROPEAN ASSOCIATION FOR PALLIATIVE CARE: <http://goo.gl/o7kN3W> [Scroll down to International Palliative Care Resource Center – IPCRC.NET]

HUNGARY | Hungarian Hospice Foundation: <http://goo.gl/5d1l9K>

U.K. | Omega, the National Association for End-of-Life Care: <http://goo.gl/UfSZtu>

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *CANADIAN FAMILY PHYSICIAN*, 2017;63(5):351-352. ‘**End-of-life care.**’ Most people in Canada do not get to die as they would like to – at home, with loved ones and without suffering. Dr. Ladouceur’s [recent] editorial¹ is one example of the current quality of end-of-life care and of the confusion of the terms surrounding it – euthanasia, physician-assisted death, physician-hastened death, palliative care (PC), and, in his article, medical aid in dying (MAiD). What morally differentiates these terms is the ethic of intention, of beneficence and self-determination. All terms relate to relief of suffering. Only PC provides a continuum of ongoing care managed by the patient, family members, and caregivers. In the case example given in Dr. Ladouceur’s editorial, the patient died suffering and his family suffered, and the discussion of MAiD is sadly ironic because the principal reason for requesting the means to one’s own death is the fear of suffering. Nonetheless, the term MAiD is misleading: it is not aid in dying, but rather aid in suicide. Physicians do assist in the process of dying – it is called relief of suffering. That said, physicians relieve suffering in the process of saving lives as well. However, in the instance given, death was imminent. The patient’s daughters wanted the suffering to end and to achieve this they were willing to accept the risk of death for the benefit of relief. Thus, they implied an informed consent along with the acceptance of the double effect of palliative sedation. This is morally acceptable albeit perhaps for some morally distressing. The family’s focus was on the suffering, while the physician’s focus was on the dying. Suffering and dying need to be distinguished. <https://goo.gl/wKdnWW>
1. ‘Medical aid in dying,’ *Canadian Family Physician*, 2017;63(1). <https://goo.gl/9IE2Jn>

Worth Repeating

The importance of following the money in the development and sustainability of palliative care

PALLIATIVE MEDICINE, 2013;27(2):103-104. Questions about cost-effectiveness and efficiency of health care are universal across developed economies, regardless of the underlying political economy of a given country or the financing of its health-care system. The articles from Klinger *et al*¹ regarding home-based palliative care (PC) in rural Ontario, and from Roberts and Hurst,² regarding inpatient PC unit staffing in England, are two cases in point. As our field continues to mature and develop, we can expect to see more of such studies taking place worldwide, because they shed much-needed light on management and sustainability issues in specialist PC. The study from Roberts and Hurst makes salient the point that sustainability in our field involves not only monetary inputs (resources, represented as costs), but also workforce availability. Availability is influenced by many factors across the world, including funding for specialist education and training, as well as issues of satisfaction, burnout, and turnover among specialist staff. Klinger *et al* go beyond a snapshot of current practices and attempt projections of what future, broader utilization could look like. <https://goo.gl/bF8f21>

1. ‘Resource utilization and cost analyses of home-based palliative care service provision: The Niagara West End-of-Life Shared-Care Project,’ *Palliative Medicine*, published online 16 January 2012. [Noted in Media Watch 23 January 2012] <https://goo.gl/JkDK2w>
2. ‘Evaluating palliative care ward staffing using bed occupancy, patient dependency, staff activity, service quality and cost data,’ *Palliative Medicine*, published online 11 June 2012.. <https://goo.gl/ReywOp>

Barry R. Ashpole
Guelph, Ontario CANADA

‘phone: 519.837.8936
e-mail: barryashpole@bell.net